

#### IV. PART C: FAMILY-CENTERED SYSTEM OF SERVICES

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Research has shown that improved outcomes for young children are most likely to occur when services are based on the premise that parents or primary caregivers are the most important factors influencing a child's development. Family-centered practices are those in which families are involved in all aspects of the decision-making, families' culture and values are respected, and families are provided with accurate and sufficient information to be able to make informed decisions. A family-centered approach keeps the focus on the developmental needs of the child, while including family concerns and needs in the decision-making process. Family-centered practices include establishing trust and rapport with families, and helping families develop skills to best meet their child's needs.

Parents and other family members are recognized as the linchpins of Part C. As such, States must include parents as an integral part of decision-making and service provision, from assessments through development of the IFSP, to transition activities before their child turns three. Parents bring a wealth of knowledge about their own child's and family's abilities and dreams for their future, as well as an understanding of the community in which they live.

In 1986, Part C of the IDEA was recognized as the first piece of Federal legislation to specifically focus attention on the needs of the family related to enhancing the development of children with disabilities. In enacting Part C, Congress acknowledged the need to support families and enhance their capacity to meet the needs of their infants and toddlers with disabilities. On the cutting edge of education legislation, Part C challenged systems of care to focus on the family as the unit of services, rather than the child. Viewing the child in the context of her/his family and the family in the context of their community, Congress created certain challenges for States as they designed and implemented a family-centered system of services.

##### Validation Planning and Data Collection

The Part C Self-Assessment noted a number of improvements that are needed to provide a Statewide family centered system of services, such as (1) need to establish a more uniform system of outreach activities by the Regional family support staff; (2) need for increased family support options, e.g. child care, respite care; (3) need to develop a uniform statewide method for gathering family satisfaction information on a regular basis (Currently local providers and regions conduct surveys but this information is not aggregated at the State level); and, (4) need for a significant increase in ongoing training for families, regarding such areas as procedural safeguards and IFSP procedures.

The public forum participants reported that: (1) consideration of family supports and services during the IFSP process needs to greatly improve; (2) the IFSP process is not well understood by most families; (3) fathers want to have greater opportunities to be included in IFSP decisions and services; (4) interagency collaboration is needed to promote development of family support services; and (5) the shift to services in natural environments has led to increased isolation of families.

During the data collection phase of OSEP's involvement with NJ, OSEP learned that one local early intervention provider, Virtua Memorial Hospital in Mt. Holly, has numerous and effective family support activities, including sibling education and support. This program offers innovative and varied family support opportunities that include support groups for fathers, sibling support, social gatherings for families, topical training (sign language, communication development, orientation to early intervention), a library story hour for all children in the community, play groups held in family homes or community locales, and informational workshops.

OSEP also learned that an "empowerment zone family support model" is supporting inner city families in Camden to participate in the early intervention system. Because inner city families often face seemingly insurmountable problems such as poor housing, lack of food and clothing, no transportation and limited access to basic medical care, early intervention providers and community agencies have formed a consortium to assist families and children in Camden. 83% of families who received early intervention services stayed involved with the early intervention system until their children exited at age 3. Prior to the formation of the consortium, approximately 20% of families stayed involved.

OSEP reviewed and analyzed the data and identified the following strengths, area of noncompliance, and suggestions for improved results for infants, toddlers and their families.

#### **A. STRENGTHS**

##### **1. DHSS Supports Family Initiatives**

DHSS makes consistent and extraordinary efforts to ensure that parents have input into all aspects of policy development and to provide financial support to parent sponsored organizations. The Chairperson of the State Interagency Coordinating Council must be a parent and all work groups must have at least one parent member. DHSS provides staff support to the Council to ensure parents have the support they need to fully participate. Early intervention contractors must set aside a portion of their annual funds so that families can attend and participate in training and advisory activities. Parents comprise at least 51% of the membership on the four Regional Collaborative boards and participate in oversight activities as volunteers, such as on-site monitoring.

Further, DHSS provides financial support for the Parent Training and Information Center to operate three projects: Project Care, Parent-to-Parent, and the New Jersey Chapter of Family Voices. Project Care, operated out of 11 county case management units throughout the State, provides support for families exiting the Part C system with fourteen paid parents. Parent-to-Parent is a telephone support service that matches trained volunteer parents with other parents with similar concerns. The New Jersey Chapter of Family Voices provides education, advocacy, and outreach to families of children with special health care needs.

##### **2. Parents as Key Regional Staff**

One aspect of the Regional Early Intervention Collaboratives' mission is to ensure that the early intervention system is responsive to local needs of families. At least one parent of a child with disabilities (Family Support Coordinator) is a paid staff member with responsibilities to develop and evaluate outreach activities, respond to phone inquiries from parents and disseminate information to parents. This Coordinator may also participate in monitoring.

### **3. Reporting Data to Promote Accountability**

DHSS disseminates information to stakeholders, including parents, about challenges in the system, thus creating an open atmosphere that helps to promote continuous improvement and accountability at the state, regional and local levels. For example, in 1998, DHSS created a Procedural Safeguards Coordinator position to ensure that families have access to a due process system that is family friendly, impartial and designed to result in speedy resolution of inquiries and complaints. OSEP reviewed documents verifying that the Procedural Safeguards Coordinator, Part C staff, and Regional staff are directing their attention to issues that result from parent phone inquiries as well as informal and formal complaints. State staff is intervening with site visits and verbal and written guidance in instances that warrant this attention. DHSS widely disseminates quarterly reports outlining these activities to the State Interagency Coordinating Council, the New Jersey Parent Training and Information Center, the New Jersey Protection and Advocacy Organization, Mediators and Hearing Officers, Regional staff and early intervention providers.

## **B. AREA OF NONCOMPLIANCE**

### **Inadequate Identification of Family Supports and Services in IFSPs**

The IFSP results from a family-centered process of identifying child and family strengths and needs. The Part C regulations require that, with the concurrence of the family, a family directed assessment be conducted to determine the resources, priorities and concerns of the family and the identification of supports and services necessary to enhance the family's capacity to meet the developmental needs of the child. 34 CFR §303.322(d). Moreover, 34 CFR §303.344 (b) requires the IFSP to include, with family concurrence, a statement of the family's resources, priorities and concerns related to enhancing the development of the child. The IFSP must also include the specific early intervention services to meet the unique needs of the family and the outcomes to be achieved for the family. 34 CFR §303.344(c) and (d).

The family-centered approach envisioned by Part C emphasizes the identification, with family concurrence, of resources, priorities and concerns and services and supports necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability. This approach can include providing services to enhance the family's skills and knowledge about their child's condition; developing outcomes on the IFSP that are functional for the family (for example, facilitating the child's sleeping, eating, playing and communicating); supporting families to gain access to services that address their needs through community agencies and providing or referring families to social support networks.

OSEP finds that the State is not ensuring that, with the concurrence of the family, IFSPs include the services and supports necessary to enhance the family's capacity to meet the developmental needs of their child.

DHSS policies and procedures instruct teams to conduct a family assessment, with family consent, during the intake, evaluation and assessment process, and to ensure that, if family needs are identified, they are discussed at the IFSP meeting. In addition, DHSS provides training to all service coordinators and providers about the process for completing the IFSP form, including identification of family concerns, priorities, resources and needs as well as services and support. However, DHSS told OSEP that it did not have an effective mechanism to track Statewide gaps in the provision of family supports and services identified by IFSP participants as a required IFSP service or "other service". The State hopes to rectify this problem with the initiation of a management information system called "One Ease E-Link" that is under construction.

In spite of DHSS's guidance and training, 13 of the 34 IFSPs OSEP reviewed did not include any information regarding family's priorities, concerns, resources, services or supports, and their children's files did not include any indication that the families had been informed of and rejected the option to have a family assessment. In the other 21 IFSPs, OSEP did find families' concerns, priorities and resources, but the IFSP did not contain any outcomes or services to address the needs even though families requested parent support services. In a few records, OSEP noted progress notes indicating that referrals had been made to community resources, such as WIC and childcare.

Interviews with Regional and Part C staff as well as reviews of State monitoring reports corroborate OSEP's finding that family services and supports are not included on IFSPs linked to the family identified needs. The Steering Committee reported that family concerns and needs are not consistently identified throughout the State and when identified, not linked to IFSP services. The Stakeholder group, Steering Committee, and other State agencies reported to OSEP that a statewide system to provide family supports and services is not yet in place. These groups mentioned the need to have accessible resource directories and to develop respite services.

In three counties OSEP visited, staff reported that they are beginning to mobilize and network agencies to address the gaps in family supports and services. County interagency representatives in the fourth area reported to OSEP that they already had close working relationships with agencies that provide family support services and were linking families to these agencies. However, at the time of OSEP's visit, OSEP did not observe the outcomes of family support linkages in any of these areas because they were not documented in progress notes, or in IFSPs, or reported in parent interviews.

In three of the four areas OSEP visited, parents reported that they feel extremely isolated in their respective communities and do not know where to go to obtain family supports and services, such as respite, information and parent support. In one community, the families established a support group to fill the need. These families suggested that having a written compilation of family resources and a hotline to obtain answers to questions about their children with disabilities would be very useful. In one county, families told OSEP that supports such as parent-to-parent, literacy programs, parenting courses, parent/child playgroups and transportation

to the toy-lending library are not available. Only one parent OSEP interviewed reported that she was aware of the Parent-to Parent program although early intervention contractors are required to disseminate this information to families as a stipulation of their state contract.

DHSS agrees that improvements are needed in New Jersey's current system of family supports and services. Prior to OSEP's visit, DHSS initiated a number of strategies to address gaps in family supports and services. A Stakeholder Service Delivery Task Force, comprised of parents, providers and agencies, submitted specific recommendations with concomitant timelines to address gaps in the provision of family supports and services. These recommendations were endorsed by DHSS. DHSS required each county to submit a Family Support Plan containing objectives and strategies to mobilize agencies, parents and others to begin to address family resource needs. DHSS provided additional funding to support one full time Regional Family Support Coordinator to assist DHSS in developing and implementing a State plan to address gaps in family resources and services. This person will work with other Regional Family Support Coordinators so that consistent activities are implemented in each Region. The State Interagency Coordinating Council's Family Support Workgroup plans to hold parent education forums and to develop parent mentoring and parent leadership training.

DHSS will need to evaluate the results of these steps and be able to demonstrate compliance with the requirements for the provision of family supports and services based on the needs identified through the IFSP process.

### **C. SUGGESTIONS FOR IMPROVED RESULTS**

#### **1. Ensuring Parents Understand the Early Intervention System and their Rights**

During the validation planning and validation data collection visits, many parents reported to OSEP that they did not understand how the early intervention system operates or who to call when they have questions about early intervention services. Many parents also stated that they were confused by the IFSP process and would have appreciated an orientation to the IFSP prior to their first IFSP meeting. Although each Region reported to OSEP that family satisfaction surveys are conducted, the families OSEP interviewed were not aware of the surveys and other mechanisms to provide feedback to the early intervention program. The Steering Committee reported a need for a significant increase in ongoing, accessible training for family members to ensure their equal partnership in the development of their child's IFSP. The fact that families are reporting a lack of understanding of the IFSP process may indicate that service coordinators are not able to provide family training and support and carry out all of their responsibilities under Part C. See Section III in this Report.

In a related matter, DHSS is re-instating a 3-hour parent-training program on procedural safeguards. This training is being initiated, in part, because of the inquiries and complaints the State is receiving from parents and findings from State monitoring. DHSS staff, in collaboration with the Parent Training and Information Center, plans to offer families 12 training sessions throughout the State.

OSEP suggests that the State continue to implement strategies to ensure that families have the information and training they need to be active participants in the early intervention system.

## **2. Promote Interagency and Broad-Based Plans for Family Supports and Services**

As DHSS moves forward with initiatives to address the needs of families within the early intervention system, OSEP recommends that two key issues be considered and explored. The first relates to coordination between agencies. Since no one agency or organization can provide all the services families may need, interagency coordination and inter-organizational arrangements are critical to ensuring a family's access to supports and services, including respite services, child care, interpreters, and transportation. The Part C program was envisioned as a coordinated system of shared responsibility and shared resources.

The second issue relates to achieving a common understanding about the parameters of family supports and services in the State's early intervention system. Many providers, administrators, service coordinators, and agency personnel equated family supports with family support groups. Family supports and services in early intervention can also include the provision and mobilization of child learning opportunities in the family's community, parent training, and family/community resources that strengthen and support families who have children with disabilities. As one Regional staff person told OSEP, "The philosophy we need to impart to the staff is that we are here to help the family and child. Early intervention helps to empower the family and help them identify the supports that are long lasting."